

Neuromuscular Services

An information guide



Neuromuscular Services

Where and when can I be seen in clinic?

Consultant led clinics - Providing diagnostic services, advice and support to patients referred into the Neuromuscular service.

For information on how to refer or be referred into the service please contact 0161 206 2010 or email us via MDU@nca.nhs.uk.

Myotonic Dystrophy Nurse led clinics -The Myotonic Dystrophy clinics are led by a neuromuscular specialist nurse, a care advisor and a physiotherapist.

We are an Outpatient team who are based at Salford Royal NHS Foundation Trust. If you require therapy at home we can refer you to local services.

We see anyone that has a Neurology Consultant at Salford Royal and has a neuromuscular diagnosis.

Fascioscapulohumeral Muscular Dystrophy (FSHD) clinics - Specialist clinics supporting patients with FSHD in the Greater Manchester area based at Salford. Clinics support patients to live well with their neurological condition and also offer the opportunity for patients to be directly involved in clinical research.

Spinal Muscular Atrophy Service - The North West's leading provider of clinical assessment clinics for patients with spinal muscular atrophy (SMA) wishing to start treatment including:

- Consultant led assessment and follow up clinics.
- Physiotherapist support, assessment, and monitoring.
- Nurse led follow up clinics.
- Multidisciplinary team working and decision making.
- Treatment with appropriate technologies.
- Patient involvement with clinical research.

Neuromuscular Nurse Led Clinics at Salford & Withington - Providing holistic care to the wider neuromuscular patient community; supporting people to live well with their neuromuscular condition through the use of evidence based practice, national guidelines and national standards of care.

Occupational Therapy

What is an Occupational Therapist?

Occupational therapists work in a variety of settings. The aim in the neuromuscular setting is to provide practical support to enable you to maintain your independence and overcome any barriers that prevent you from doing the activities (occupations) that matter to you. The goal is for you to feel empowered to manage your long term condition.

How can an Occupational Therapist help me manage my long term condition?

There are many different ways in which an Occupational Therapist can work with you. Key areas that maybe discussed are:

1. Developing your skills, knowledge and confidence in managing your condition to maintain participation in the activities you want to do.
2. Analysing where you are completing the task and if there any barriers and ways to adapt this to continue to participate.
3. Considering how you approach completing an activity. This may or may not require a discussion about equipment.
4. Exploring ways to participate in an activity in the most effective way.
5. Providing symptom specific advice and education; for example fatigue, stress and relaxation, changes in hand function.

6. Engaging in education and support to other health professionals that you are working with.

7. Referral to local services if you require assessment in your own home or other relevant services.

How can I contact the Neuromuscular Occupational Therapist?

You can ring us on 0161 206 2010 and if you cannot speak to us directly, please leave a message and we will get back to you either the same day or as soon as possible. We can discuss your concern via telephone or you can have a one to one appointment with us.

Physiotherapy

What is a Physiotherapist?

Physiotherapists help people affected by injury, illness or disability through movement and exercise, manual therapy, education and advice. They maintain health for people of all ages, helping to manage pain and prevent disease.

How can a Physiotherapist help me manage my long term condition?

1. Assess and explain physical symptoms and how these can be managed proactively throughout the course of the condition.
2. Explore the use of certain orthotics and refer appropriately.
3. Help to manage falls risk.
4. Advice regarding walking aids.
5. Manual therapies.
6. Advice on exercise for health and more specific exercises.
7. Education and support to other professionals that you are working with.

8. Refer to local physiotherapy services if multiple treatment sessions are required or it is more appropriate for you to be seen in your own home.

How can I contact the Neuromuscular Physiotherapist?

You can ring us on 0161 206 2010 and if you cannot speak to us directly, please leave a message and we will get back to you either the same day or as soon as possible.

We can discuss your concern via telephone or you can have a one to one appointment with us.

Neuromuscular Specialist Nurse & Care Advisors

How can a Neuromuscular Advisor help me?

Neuromuscular advisors provide practical and emotional support for families affected by neuromuscular conditions.

They offer advice and information to support physical and emotional wellbeing. Neuromuscular advisors can also provide condition-specific information to families, schools, colleges, employers, or other professionals.

They can offer advice on benefits and other entitlements. They work in partnership with statutory service providers, education authorities and other professionals to provide an holistic approach to patient-centred care.

How can I contact a Neuromuscular Advisor?

You can ring us on 0161 206 2010 and if you cannot speak to us directly, please leave a message and we will get back to you as soon as possible.

We can discuss your concern via telephone, or you can have a one to one appointment with us at the hospital.

Alternatively, you can also email us by using our dedicated patient email address: MDU@nca.nhs.uk

Neuromuscular Nurse

Self-refer to one of our telephone clinics

Our Neuromuscular specialist nurse is available for advice and support of patients with neuromuscular conditions.

If you have any concerns about your symptoms or condition you can call and speak to our Medical Secretary who will triage you into one of our telephone or face to face clinics.

Follow up appointments typically take place six-twelve monthly.

Occupational Therapist

TBC

Neuromuscular Nurse & Care Advisor

0161 206 2010

MDU@nca.nhs.uk

Physiotherapist

0161 206 2010

MDU@nca.nhs.uk

Medical Secretaries

Salford - 0161 206 2010 / MDU@nca.nhs.uk

Withington - 0161 291 4272

SMA clinic co-ordinator

0161 206 4431

Notes

Copies of this leaflet are available in other formats (e.g. large print or easy read) upon request. Alternative formats may also be available via:

 www.northerncarealliance.nhs.uk

In accordance with the Equality Act we will make reasonable adjustments to enable individuals with disabilities to access our services. Please contact the service or clinic you are attending by phone or email to discuss your requirements.

If you need this leaflet in a language other than English please contact the NCA Central Interpretation Booking Office via the following details:

 **0161 627 8770** or Email:  Interpretation@nca.nhs.uk

 **07966 003 540** Mobile Text

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 Main switchboard: **Bury, Oldham & Rochdale - 0161 624 0420**

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